

Eur J Epidemiol (2007) 22:483–485  
DOI 10.1007/s10654-007-9155-9

COMMENTARY

## From evidence based bioethics to evidence based social policies

Luc Bonneux

Received: 1 June 2007 / Accepted: 14 June 2007 / Published online: 27 July 2007  
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**Abstract** In this issue, Norwegian authors demonstrate that causes of early expulsion out the workforce are rooted in childhood. They reconstruct individual biographies in administrative databases linked by a unique national identification number, looking forward 15 years in early adulthood and looking back 20 years till birth with close to negligible loss to follow up. Evidence based bioethics suggest that it is better to live in a country that allows reconstructing biographies in administrative databases than in countries that forbid access by restrictive legislation based on privacy considerations. The benefits of gained knowledge from existing and accessible information are tangible, particularly for the weak and the poor, while the harms of theoretical privacy invasion have not yet materialised. The study shows once again that disadvantage runs in families. Low parental education, parental disability and unstable marital unions predict early disability pensions and premature expulsion out gainful employment. The effect of low parental education is mediated by low education of the index person. However, in a feast of descriptive studies of socio-economic causes of ill health we still face a famine of evaluative intervention studies. An evidence based social policy should be based on effective interventions that are able to break the vicious circles of disability handed down from generation to generation.

**Keywords** Norway · Epidemiology · Pensions · Disability · Risk factors · Educational status · Socioeconomic factors · Databases

Natural selection is for biology what the human life course is for epidemiology: an overarching framework needed to understand the occurrence of disease in the biography of the individual person [1]. The life course of human beings as a history of health and disease starts long before conception, in the genes and life course of their parents. The odds at facing a successful life are entirely different if conception started with the rape of a young teenager by an HIV positive warrior in a horrifying African civil war or as the consequence of the deep desire to raise a child among a healthy and wealthy European loving couple. To expect a life in good health, healthy parents have to provide their offspring with good genes, food, shelter, love, an upbringing and an education.

However, a general problem of human life course epidemiology is that the human life course is a lot longer than the scientific career of epidemiologists. While there is a scope for ambitious programmes of prospective research spanning multiple generations, such programmes will nevertheless run into questions not addressed by the original design. In this issue, the Norwegian study of Gravseth et al. show how existing data from administrative databases can be put to good use to understand disabling processes originating in youth [2].

### Evidence based bioethics

As in other Scandinavian countries, several databases (here the medical birth registry, benefit and income registries in the National Insurance Administration, the education register of Statistics Norway, and the Central Population Register) can be linked by a unique national identification numbers of the child and the parents. In many European countries, such linkage is considered a breach of personal

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L. Bonneux (✉)  
NIDI, PB 11650, Den Haag, 2502 AR, The Netherlands  
e-mail: [bonneux@nidi.nl](mailto:bonneux@nidi.nl)

autonomy through invasion of privacy. Bioethical theory is very concerned with the potential of abuse of knowledge, but seems to neglect the potential of harm by lack of available but inaccessible knowledge [3]. Gravseth et al. shows how linked administrative databases can yield important insights in the human life course, supporting policy decisions protecting the poor and the weak. Bioethical theory mistrusts human nature, suggesting that the risk of abuse of private information from linked administrative databases is high. This has never been confirmed by empirical evidence. Bioethics should consider the possibility that untested theories supported by unproved assumptions may look good in theory, but in practice waste healthy life. Medicine knows a large array of such theories. Although critical of parenting experts, we too put our first babies to sleep on their front, likely following advice that started by the celebrated parenting expert, Dr Spock. In 1970, a statistically significantly increased risk of cot death for front sleeping compared with back sleeping (pooled odds ratio 2.93; 95% confidence interval 1.15, 7.47) could already be identified from the then available studies [4]. Preferring the cool theory of babies developing their brain and body better by looking up to spot their mother over the neglected harsh evidence has caused the death of 50,000 babies worldwide, this after 1970 only [4]. Where empirical investigation is possible, bioethical theory needs corroboration by observable evidence [5]. If evidence of harms and benefits is available, as with the long-standing practice of data linkage in the Scandinavian countries, observable evidence of benefits should have precedence over theoretical considerations based on unproved assumptions.

### The use of administrative databases

The use of administrative databases can be very tantalising: they carry a lot of information, but what one wants is not available or not reliable [6]. However, as in all study designs, its' use depends on one's aims. Flagging persons in a population register and being informed by a mortality register of their death will obtain survival figures at low costs. Death is one of those few health states even epidemiologists do not argue about. Follow up is always close to 100%.

An important principle of administrative databases is that they don't follow patients but money. As soon as money is at stake, administrative registers become highly reliable to count processes amenable to financing, and loss to follow-up is close to negligible. Eligibility for benefits may change over periods, but the fact of being reimbursed is coded extremely well. One of the strong characteristics of administrative databases is their completeness, even

over very long periods. In the article of Gravseth et al., early disability pension registered in 1988–2003 is a highly reliable proxy of definitive expulsion from paid work. Looking back to the medical birth registry in 1967–1976 and a limited number of parental characteristics between ages 0 and 18 of the child, the authors have explored the consequences of a limited numbers of determinants in youth for later expulsion out of work.

### Shaping the life course

Losing the capability to do paid work between the ages 20 and 35 is a highly relevant health outcome, as defined by Sen's capability approach [7]. Being unable to work at young adult age is a heavy burden of disability. In terms of attributable risks, education is by far the most important determinant, explaining 57% of the risk of early disability. Here, the administrative data show their inherent weakness: they contain little information of the process leading to low levels of education, be it personal factors related to the health of the child or social factors related to its' family and living situation. However, the stratified analysis suggests that low education of the child finds its roots in low education of parents. It is worrying that even in a country as Norway, with one of the highest human development indices in the world, disadvantage as expressed by low education of parents and parental disability is still handed down from generation to generation. Last but not least, the relative importance of maternal marital status shows the importance of stable marital unions to raise healthy children. With low European fertility and postponement of first pregnancy after the age of 30, policy makers are tempted to try to push women into earlier childbirth. This policy may be ill advised, if it leads to more children of less well educated younger mothers in less stable unions.

### Moving to evidence based policy

Gravseth et al. show, by using linked administrative databases, that causes of early disability in young adulthood are rooted in childhood and in parental disadvantage. A consequence is that interventions targeting the adults at risk will likely add more to the problems than to the solutions. The horns of the dilemma to give or to withhold a disability pension are terribly sharp. An early disability pension is a social death sentence, crippling the individual by removing incentives to seek work and declaring him or her definitively incurable. But those who are effectively crippled won't be helped by the misery of repeated frustrations in a labour market in which they cannot compete. Studies

carefully designed to identify determinants of irreversible disability are needed, inclusive randomised controlled experiments evaluating pension decisions as important health care interventions.

I opened this editorial by making the strong comparison between the little African girl, pregnant after being raped and the highly educated European women in her 30s. However, even in Norway, disadvantage is still a disease that runs in families. We have now a descriptive feast of the lifelong health consequences of social disadvantage and low education. However, the evidence supporting effective interventions is remaining an evaluative famine [8]. Successful interventions need to target the vicious circles of disadvantage that are handed down from generation to generation. We need theories and models that identify potentially effective interventions and study designs able to collect the evidence that supports the effectiveness. The transgenerational aspects of life course epidemiology may be a hard nut to crack in evaluative research. But as good health starts with a good education, good education will always be a worthy proxy.

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